

young

Women's Initiative

Arin Ahlum Hanson, MPH, CHES
Manager, Young Women's Initiative
arin@lbbsc.org



**LIVING BEYOND
BREAST CANCER**

Presentation Overview

1. Living Beyond Breast Cancer Overview
2. LBBC Programs and Resources
3. LBBC's Young Women's Initiative
 - YWI Programs: Online
 - YWI Programs: By Phone
 - YWI Programs: In Print
 - YWI Programs: In Person
 - YWI Programs: Healthcare Provider Education
4. Ways to Get Involved



LIVING BEYOND
BREAST CANCER

LBBC History and Overview

- National nonprofit founded in 1991.
- Among the first to fulfill the need for breast cancer-related information, connection and support after treatment.
- As the need for specialized services increased, LBBC expanded to assist women at all stages of diagnosis, treatment and survivorship.
- Tailored programs and resources for young women, women diagnosed with triple-negative breast cancer, women living with metastatic breast cancer, African-American women, among others.
- Reaches over 500,000 people affected by breast cancer and their families each year!



**LIVING BEYOND
BREAST CANCER**

LBBC'S MISSION



TO CONNECT **YOU** WITH TRUSTED BREAST CANCER
INFORMATION AND A COMMUNITY OF SUPPORT.

ABOUT LBBC



Online



In print



By phone



In person

Programs and services are available in different formats to accommodate the individual preferences of users.



**LIVING BEYOND
BREAST CANCER**

LBBC Programs

- National conferences
 - Thriving Together: 2016 Conference on Metastatic Breast Cancer (April 8-10, Philadelphia)
 - Annual Fall Conference (Sept 23-24, Philadelphia)
 - Webinars
 - Breast Cancer Helpline, peer-to-peer telephone and online chat support
 - lbbc.org, our interactive website
 - Twitter Chats
 - Breast Cancer 360s - live web-streamed panel discussions
-and More!



**LIVING BEYOND
BREAST CANCER**

LBBC Publications

Insight- LBBC's quarterly newsletter

Early-Stage Series

- Guide for the Newly Diagnosed
- Hormonal Therapy
- Triple-Negative Breast Cancer
- Fear of Recurrence
- Treatment Decisions
- Understanding Your Emotions

Metastatic Series

- Guide for the Newly Diagnosed
- Managing Stress and Anxiety
- Treatment Options
- Understanding Palliative Care

General Titles

- Intimacy and Sexuality
- Insomnia and Fatigue
- Yoga and Breast Cancer
- Lymphedema
- Financial Concerns
- Bone Health

inFocus Series

- Getting the Care You Need as a Lesbian, Gay or Bisexual Person
- Pregnancy and Breast Cancer (Coming Soon!)
- Men and Breast Cancer (Coming Soon!)

Young Women's Initiative

- LBBC has been offering programs and services specific to young women since our founding in 1991.
- Through 3-year cooperative agreement with Centers for Disease Control and Prevention, Young Women's Initiative (YWI) was launched in Nov 2011. (DP11-1111)
- Expands and strengthens LBBC's existing programs for young women while developing new programs and resources for this community.
- Over 100,000 young women and their families have been reached through YWI since 2011.
- In Oct 2014, LBBC received a second cooperative agreement through the CDC to continue to expand YWI. (DP14-1408)



**LIVING BEYOND
BREAST CANCER**

Program Priorities Selected

1. Developing tailored online resources for young women.
2. Increasing opportunities for young women to receive peer support through LBBC's Breast Cancer Helpline.
3. Educating healthcare providers about the unique needs of young women affected by breast cancer.
4. Expanding our programming and resources for key groups we determined to have unique needs and to be underserved.



**LIVING BEYOND
BREAST CANCER**

YWI – Online

- lbbc.org/youngwomen
- Developed over 120 website articles specific to young women, including easy-to-read summaries of breast cancer research studies and profiles.
- Twitter Chat- May 18
 - Young women living with metastatic breast cancer
- Breast Cancer 360 – July 14, 2016, Denver, CO
 - Focused on sexual health and dating issues for young women
- Webinars focused on young women's needs
 - Ovarian Suppression Webinar – January 2015



**LIVING BEYOND
BREAST CANCER**



“Let’s Talk About It”

Video Series for Young Women



Watch at lbbc.org/letstalk



**LIVING BEYOND
BREAST CANCER**

Connecting you

to trusted breast cancer information and a community of support

Let's Talk About It Video Series

- Beyond the Shock: Young Women Reflect on the Impact of Breast Cancer
- Hot in Here: Coping With Symptoms of Early Menopause
- Been There, Done That: Advice From Other Young Women
- Body Image: Tips and Truths
- Financial Impact of Breast Cancer
- Let's Talk About Sex (And Breast Cancer)
- Hear Me: Communicating with Your Healthcare Team
- What Young Women Should Know About Bone Health

Metastatic Series

- Tired of It: Young Women, Metastatic Breast Cancer and Fatigue
- A New Reality: Young Women Discuss Living With Metastatic Breast Cancer
- Getting Support You Need As a Young Woman Living with Metastatic Breast Cancer
- Having Hard Conversations as a Young Woman With Metastatic Breast Cancer
- Coping With Other People's Reactions to Metastatic Breast Cancer



**LIVING BEYOND
BREAST CANCER**

Watch at lbbc.org/letstalk

YWI- By Phone

Helpline

- Trained 45 young women to serve as new Helpline volunteers since 2011.
 - 58 out of 128 (45%) active Helpline volunteers were diagnosed before age 45.
- Launched online chat in September 2015

YWiConnect Text Messages

- Launched text message service for YWI program notifications in June 2015. Send out 3 texts a month.
- 134 subscribers. Goal of 300 subscribers by June 2016.



TEXT LBBC TO 25827

YWI- In Print

- Developed new print publications on topics of high interest to young women. They included:
 - *Guide to Understanding Intimacy and Sexuality*
 - *Guide to Understanding Hormonal Therapy*
 - *Guide to Understanding Genetics and Family Risk*
 - *Guide to Understanding Complementary Therapies*
 - *Guide to Understanding Financial Concerns (update)*
 - *inFocus: Getting the Care You Need as an LGB Person*
 - *inFocus: Pregnancy and Breast Cancer (Coming soon!)*



**LIVING BEYOND
BREAST CANCER**

YWI- In Person

- Increased programming and connection for young women at LBBC's conferences
 - 1/3 of audience are young women
 - YWI Hosted Happy Hour
 - Workshop offerings focused on the needs of young women
- Regional Partnered Symposiums
 - Breast Cancer Breakthroughs with Abramson Cancer Center Hospital of University of Pennsylvania



LIVING BEYOND
BREAST CANCER

YWI- In Person

Young Advocate Program

- Helps young women use their personal experience to make a difference in their communities.
- Targets women with limited incomes and who are within three years of diagnosis.
- 8-14 hour in-person training covers topics on advocacy, breast cancer disparities and how to share one's story cancer.
- Program participants are required to complete two activities and share LBBC's resources with at least one contact within six months of training.



**LIVING BEYOND
BREAST CANCER**

Young Advocate - 2015

- **127** young women applied to the program
- **29** Young Advocates were trained, growing our Young Advocate community to **76**
- Our Young Advocates hail from **28** different states
- **50+** outreach activities have been reported
- **5,295** LBBC educational materials were distributed by Young Advocates in 2015



LIVING BEYOND
BREAST CANCER

76 Young Advocates!!



YWI - Healthcare Provider Education

- Developed programs to educate healthcare providers on the unique needs of young women and help them develop the skills needed to address these needs.
- Targeting oncology nurses and oncology social workers
- Held 4 webinars - more than 1,000 healthcare providers have participated. 40% were new to LBBC.
- Held two half day healthcare provider symposium in conjunction with Association of Oncology Social Work Annual Conference.
- Upcoming Webinar
 - March 23, 12-1pm “Understanding the Unique Needs of Your Metastatic Breast Cancer Patients” with Pamela Ginsberg, PhD



**LIVING BEYOND
BREAST CANCER**

Ways to Get Involved

- Join our YWI Outreach Network and share our programs announcements with young women.
- Share *Let's Talk About It Videos* on social media and/or embed them on your website.
- Order LBBC's Publications and distribute them to young women or healthcare providers.
- Provide your expertise as a speaker, medical or consumer reviewer.



LIVING BEYOND
BREAST CANCER

young

Women's Initiative

Questions?

Arin Ahlum Hanson, MPH, CHES
Manager, Young Women's Initiative
arin@lbbsc.org



LIVING BEYOND
BREAST CANCER